Editorial

Targeting health care improvement for persons with disabilities

Histories of persons with disabilities only started being widely told in the last few decades, and often they are not happy. Discrimination, disenfranchisement, and even outright hostility reach back to Biblical times. The forced isolation of many persons with disabilities over the centuries has obliterated their traces. Leaping forward two millennia, enormous strides have certainly been taken, often spurred by people with disabilities themselves. Especially in developed nations, legal, economic, societal, and environmental barriers are falling, allowing persons with disabilities to participate fully in daily life throughout communities. Nonetheless, persistent hurdles do remain, even in health care.

But wait. Barriers to health care for persons with disabilities? After all, as an American presidential advisory committee on health care quality wrote, ‘The purpose of the health care system must be to continuously reduce the impact and burden of illness, injury, and disability and to improve the health and functioning of the people of the United States’ [1]. However, as amply documented by Lawthers and colleagues, the US health care system falls considerably short of these goals for persons with disabilities [2].

Within the US, the genesis of these shortcomings is obvious. Our nation does not guarantee a right to health care. Without universal health insurance, over 40 million people have no coverage, and being uninsured for 1–4 years can worsen health status [3]. Even with health insurance, persons with disabilities are often unable to receive care they need [4]. Insurers, including Medicare and Medicaid, strictly limit coverage of items and services for maintaining or restoring functioning, like long-term physical and occupational therapy, assistive devices (e.g. hearing aids, mobility aids), and even modest home modifications (e.g. bathroom grab bars) [4]. Furthermore, despite federal and state statutes requiring physical access to health care facilities, barriers remain to buildings and equipment. Lawthers et al. extend their reach beyond the traditional boundaries of health care into vocational and social services, but what about housing, basic education, nutrition, income support, telecommunications, and transportation? Every aspect of daily life ultimately weaves together, affecting people’s physical, mental, and emotional well-being.

When viewed so broadly, the challenges become overwhelming, therefore reformers need tools to get started. Lawthers and colleagues suggest new models for assessing quality, but taking the next step—improving care—could perhaps most effectively build upon existing efforts to characterize disability and guide health care quality improvement. Here, I focus on the traditional health care sector, recognizing that the boundaries blur.

Classifying disability

Disabling conditions are diverse in their causes, nature, timing, pace, and societal implications. This diversity holds implications for targeting health care quality improvement. As Mairs wrote, ‘I cannot . . . depict and analyze ‘disability’ as a global subject. The category is simply so broad, and the possible approaches to it so numerous, that all the attempts I’ve come across at generalizing about it run into difficulty’ [5]. The phrase ‘persons with disabilities’ is too broad to direct action.

Having studied disability worldwide, Charlton argued that persons who are blind or have mobility impairments are better off than those with other disabling conditions. Regardless of country or continent, ‘a hierarchy of disability’ puts persons disabled by mental illness at the greatest disadvantage, followed by those who are deaf or hard of hearing [6]. Persons with physical and visual impairments generally have the strongest support systems and greatest political, social, and economic opportunities. The observations by Mairs and Charlton therefore suggest that classifying different types and sources of disability might impose meaningful structure to help identify and target particular populations and needs.

Today, the most prominent scheme is the International Classification of Functioning, Disability and Health (ICF), approved by the World Health Organization (WHO) in May 2001 [7]. The ICF’s conceptual model offers a roadmap for designing health care improvements by identifying various factors that contribute to disability (Figure 1). The ICF adopts a biopsychosocial approach by drawing on three interrelated concepts: impairments, i.e. specific problems with body functions or structures; activities, i.e. tasks or actions performed by an individual; and participation, i.e. involvement in life situations. The ICF defines disability as an ‘umbrella term for impairments, activity limitations or participation restrictions’ ([7], p. 3), conceiving ‘a person’s functioning and disability . . . as a dynamic interaction between health conditions (diseases, disorders, injuries, traumas, etc.) and contextual factors’, including environmental and personal attributes ([7], p. 8). The ICF organizes its codes, grouped within 30 chapters, around these concepts.
Thus, the ICF’s disability definition melds diseases, disorders, and specific impairments with concerns about how human beings conduct daily activities within their environments. Critics argue that some ICF concepts require greater specification, such as the distinction between activities and participation. Nevertheless, this model suggests that outcomes of health care interventions cannot look only at treating diseases and impairments, but must also reach beyond, addressing people’s abilities to live and participate in daily life in their communities. Sometimes remedies must target environments, interventions that will benefit others beyond individual patients, i.e. classic public health.

Crossing that quality chasm

In its seminal 2001 report *Crossing the Quality Chasm*, the US Institute of Medicine observed that the American health care system fails many, including persons with serious functional limitations and disabilities [8]—a position amply corroborated by Lawthers *et al*. Moving beyond measuring quality, the *Quality Chasm* report outlined six aims to guide improvement, ensuring health care that is:

1. Safe, i.e. avoids injuring patients;
2. Effective, i.e. based on scientific evidence of benefit;
3. Patient-centered, i.e. respectful of patients’ preferences, needs, and values;
4. Timely, i.e. reduces waits and harmful delays;
5. Efficient, i.e. avoids waste of equipment, supplies, ideas, and energy; and
6. Equitable, i.e. of equal quality, regardless of patients’ personal characteristics

Each aim holds special resonance for persons with disabling conditions. Patient centeredness should perhaps lead the way. Many people with disabilities have previously had others define and circumscribe their lives and options. Persons with disabilities are significantly more likely to be dissatisfied with their clinicians’ focus on symptoms and diseases rather than overall health [9]. Reorienting health care to emphasize patients’ preferences, needs, and values represents a sea change, already underway in some venues but yet to encompass all care settings. Lack of insurance coverage for function-related therapies, assistive technologies, home modifications, personal assistance, and supportive care present significant challenges to meeting this aim.

The other five aims also carry particular relevance for persons with disabilities. People with complex diagnoses or multiple coexisting conditions are more susceptible to safety risks (e.g. they often consume more drugs, have more invasive procedures, and spend more time within the health care system). They can also suffer neglect within care settings (e.g. developing pressure ulcers). People with disabilities are typically excluded from randomized clinical trials that assess the efficacy and effectiveness of therapeutic interventions, like new drugs or surgical procedures. Therefore, minimal evidence exists to provide evidence-based care. The evidence base around assistive technologies and therapies to prevent or delay functional declines remains particularly meager.

Delays and waits affect everybody. Nevertheless, people who must depend on over-booked and financially strapped para-transit systems (i.e. public transportation, typically vans with wheelchair lifts or specially designated cars for qualifying persons with disabilities) often find themselves missing appointments or arriving late. This frustrates both patients and clinicians. More importantly, certain persons with disabilities are significantly less likely than others to receive selected screening and preventive services [10], perhaps resulting in detection at later, less treatable stages of serious diseases (e.g. breast cancer) [11]. Avoiding waste, especially of energy, is highly relevant for persons with activity limitations. Ironically, with short appointment times, persons with disabilities may need to visit physicians several times to address their health care needs fully.

Finally, equity raises particular concerns. *Healthy People 2010*, which sets national health priorities, observes that misconceptions about people with disabilities contribute to their receiving relatively fewer health promotion and disease prevention services [12]. Consequently, persons with disabilities may experience disadvantages in their health and well-being compared with others in the general population.

According to *Crossing the Quality Chasm*, the current American health care system is fundamentally incapable of providing the care patients expect or deserve [8]. Rebuilding it will require involvement from people who are particularly at risk within the present system. People with disabilities, broadly defined, fit that description. People with disabling conditions, their families, and communities should help direct fundamental redesign of American health care.

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